### **Conference Partners:**

## Association of State and Territorial Health Officials

The Association of State and Territorial Health Officials (ASTHO) is a non-profit public health organization that represents the leaders of State and Territorial health agencies. Our members work collectively to formulate and influence sound national health policy and to develop and implement state programs and policies to promote health and prevent illness and disability to improve quality of life.

## Centers for Disease Control and Prevention, HHS

The mission of the Centers for Disease Control and Prevention (CDC) is to promote health and quality of life by preventing and controlling disease, injury, and disability. In 1997 CDC established the Office of Genetics and Disease Prevention (OGDP) to provide a coordinated focus for CDC-wide, crosscutting genetics efforts with particular emphasis on communication, training, and program and policy development.

### Health Resources and Services Administration, HHS

The Health Resources and Services Administration's (HRSA) mission is to increase access to basic health care for those who are medically undeserved through support of community health centers, maternal and child programs, and health professional training programs. HRSA administers the Maternal and Child Health State Block Grants, supporting State public health agency infrastructure. The Genetic Services Branch's (Maternal and Child Health Bureau, HRSA) mission is to facilitate the early identification of children with genetic conditions to integrate them into population and community-based, family centered systems of care.

### National Human Genome Research Institute, NIH, HHS

The National Human Genome Research Institute (NHGRI) is one component of the National Institutes of Health. It is one of the lead agencies responsible for the U.S. contribution to the Human Genome Project (HGP). When completed, the HGP will provide genetic information and technologies that will result in a better understanding of genetic contributions to health and disease and allow for the development of better and more targeted treatments and prevention interventions. One critical element of the HGP has been the exploration of the ethical, legal, and social implications of the discovery and use of this information and these technologies.

This conference is being held in collaboration with the Maryland Department of Health and Mental Hygiene and the Johns Hopkins University School of Hygiene and Public Health.

# The Second National Conference on Genetics and Disease Prevention

Integrating Genetics into Public Health Policy, Research, and Practice

### Baltimore, Maryland • December 6-8, 1999

Scientific advances in genetics are creating both exciting opportunities and tremendous challenges for public health. When the Human Genome Project is completed in 2003, all of the estimated 100,000 human genes will have been sequenced. The purpose of the Second National Conference on Genetics and Disease Prevention is to address public health opportunities and challenges presented by these advances in human genetics research.

#### **Who Should Attend:**

- Public health practitioners, researchers, and policymakers at the local, state, and federal levels;
- · Interested parties from academia, industry, and the public.

### Scheduled Sessions Include:

- Genetics from a Public Health Perspective
- Developing Genetics Capacity within Public Health Infrastructure
- Emerging Genetic Technologies Implications for the Future
- A Diverse Community Perspective on Genetics Research and Testing
- Enlisting the Community as a Resource
- Preventing Disease through Genetic Knowledge: A Look at Colon Cancer
- Privacy and Confidentiality
- Financing of Public Health Functions
- Challenges for the Future: Partnerships to Improve Health

### Other Program Highlights:

- Presented papers and poster sessions from competitive abstracts.
- Concurrent sessions addressing six themes related to the use of genetics to improve health.
- Demonstrations from on-line resources such as HuGE Net, OMIM, Helix, GenLine, and InfoGen.

## **General Information**

## Baltimore, Maryland

Baltimore is known as "Charm City" you, too, will be charmed by all that Baltimore has to offer! From its famous city center, Inner Harbor, which offers fantastic shopping, dining and attractions, to its historic sites, homes and museums, to quaint neighborhoods and ethnic restaurants, Baltimore has successfully blended the old with the new.

### **Hotels**

Please contact the hotel of your choice directly to make reservations. There are no housing forms to fill-out. The cut-off date for room reservations is November 10, 1999. After that date, the rates are set at the discretion of the hotels. Make sure to request the group rate for the Second National Conference on Genetics and Disease Prevention.

# Hyatt Regency Baltimore on the Inner Harbor

300 Light Street, Baltimore, MD 21202

The Hyatt Regency Baltimore is the official headquarters hotel for the Second National Conference on Genetics and Disease Prevention. Rates: \$139/single, \$159/double plus tax (currently 12.5%). Call 410-528-1234, or 800-233-1234 for reservations.

A limited number of government rate rooms are available on a first-come, first-served basis. Ask for the Second National Conference on Genetics and Disease Prevention Government block.

### **Sheraton Inner Harbor Hotel**

300 South Charles Street, Baltimore, MD 21201

The Sheraton Inner Harbor Hotel is located directly across the street from the Hyatt Regency Baltimore. Rates: \$125/single or double plus tax (currently 12.5%). Call 410-962-8300, or 800-325-3535 for reservations.

A limited number of government rate rooms are available on a first-come, first-served basis. Proper identification is required.

#### **On-Site Registration Hours**

If you have registered in advance you may pick up your registration materials during the following hours:

Monday, December 6	7:30 am - 5:00 pm
Tuesday, December 7	7:30 am - 5:00 pm
Wednesday, December 8	7:30 am - 10:00 am

#### **Exhibit Hours**

The Conference Planning Committee is building ample time into the Conference schedule to allow conference participants the opportunity to visit the exhibits. The tentative schedule is:

Tuesday, December 7	7:30	am –	1:00 pm
Wednesday, December 8	7:30	am -	1:00 pm

### **Airline Discounts**

US Airways has been designated as the official carrier for the attendees of The Second National Conference on Genetics and Disease Prevention in Baltimore, Maryland. Additional service is available into Washington DC's Reagan National and Dulles airports. US Airways agrees to offer an exclusive low fare for the attendees. This special fare will offer a 5% discount off First or Envoy Class and any published US Airways promotional round trip fare. A 10% discount off unrestricted coach fares will apply with 7 day advance reservations and ticketing required. Plan ahead and receive an additional 5% discount by ticketing 60 days or more prior to departure. These discounts are valid provided all rules and restrictions are met and are applicable for travel from all points on US Airways' route system.

To obtain these discounts, you or your professional travel consultant must call US Airways' Group and Meeting Reservation Office toll free at (877) 874-7687; 8:00 am - 9:30 pm Eastern Time. Refer to Gold File No. **62661146**.

## **Ground Transportation**

The Baltimore/Washington International Airport (BWI) is approximately a fifteen minute ride to the city center. The taxi fare from the airport to downtown is approximately \$18.00 and the BWI Super Shuttle is approximately \$11.00 one way.

### **Car Rental**

Alamo Rent-A-Car is offering special discounted rates for The Second National Conference on Genetics and Disease Prevention. For reservations, call (800) 732-3232 or visit alamo.com and refer to Group ID Number 603967, Rate Code GR.

## **Maryland Science Center**

### Monday, December 6, 7:00 pm - 10:00 pm

Three floors of fun and fascinating interactive exhibits, the best view of Baltimore's skyline and a larger-than-life five story IMAX movie theater await you at the Maryland Science Center. Enjoy a strolling buffet dinner and cash bar in this exciting setting which is within walking distance of the hotels.

## AGENDA

## Monday, December 6

8:30 - 10:00

## **Opening Session/Keynote Address**

## **Welcoming Remarks**

**Patricia Nolan**, MD, MPH, *President, ASTHO and Director, Rhode Island Department of Health* 

Parris Glendening, Governor, Maryland (Invited)

Barbara Mikulski, U.S. Senator, Maryland (Invited)

Jennie Forehand, State Senator, Maryland

Margaret Hamburg, MD, Assistant Secretary for Planning and Evaluation, Department of Health and Human Services

### **Keynote Speaker**

#### **Overview of Advances in Human Genetics**

Francis Collins, MD, PhD

Dr. Collins will report on the accelerating pace of the Human Genome Project and the implications of its completion by the year 2003. The impact of new genetic technologies and information on the future of public health will be discussed.

10:30 - 12:00

### **Plenary Session**

### **Genetics from Public Health Perspective**

The panelists will discuss the challenges and opportunities in integrating genetics into health policy and research that must be met by public health agencies and schools of public health, and will serve as a reactive session to the vision presented by Dr. Collins in the morning's keynote address.

**Muin Khoury**, MD, PhD, Director, Office of Genetics and Disease Prevention, CDC

**Sam Shekar**, MD, MPH, Associate Administrator, Field Operations, HRSA

**Georges Benjamin**, Secretary, Maryland Department of Health and Mental Hygiene (Invited)

**Scott Zeger**, PhD, *Professor and Chair of the Department of Biostatistics, Johns Hopkins School of Hygiene and Public Health* 

12:30 - 2:00

### Luncheon

## Leadership Role of Genetics and Public Health

**David Satcher**, MD, PhD, Assistant Secretary for Health and U.S. Surgeon General (Invited)

Surgeon General Dr. David Satcher will highlight the pivotal role genetics will play in the health of the public.

2:30 - 4:00

### **Plenary Session**

## Developing Genetics Capacity within Public Health Infrastructure

Speakers will discuss strategies to enhance public health's capacity improve health through the application of genetic advances and to assure access to appropriate genetic services.

**Peter van Dyck**, MD, MPH, Acting Associate Administrator, Maternal and Child Health Bureau, HRSA

James Marks, MD, MPH, Director of the National Center for Chronic Disease Prevention and Health Promotion. CDC

William Raub, PhD, Deputy Assistant Secretary for Science and Policy, DHHS

4:15 - 5:45

#### Concurrent Sessions

## 1. The Continuity of Research: From Discovery to Utility

Using hemochromatosis as an example, this session will explore the translation of genetic discovery into public health research and practice.

### 2. Legislative and Policy Developments

Panelists will discuss the integration of genetic advances in the policy and legislative arenas, at both the national and state levels.

#### 3. Education and Information Dissemination

Speakers will provide an update and strategies for educating professionals and informing the public about the uses of genetic knowledge, with current examples.

## 4. Laboratory Technology: Quality Assurance and Policy Implications

The key laboratory issues in genetics, including the lab's role, its operations, opportunities & challenges, and needs, such as technologies, training, and partnerships will be discussed.

## 5. Assessing and Expanding Genetics and Disease Prevention Capacity

Panelists will highlight strategies for assessing and expanding the effective use of genetics information to improve health and prevent disease through pubic health practice.

#### 6. Public Health Performance Measurement

Information needs presented by the integration of genetics into public health research and practice, including quality assessment, registries, integrated data systems, and informatics issues will be highlighted.

7:00 - 10:00

## **Maryland Science Center Social Event**

## Check out the conference website:

www.cdc.gov/genetics/temporary/Conference.pdf

## **Tuesday, December 7**

7:30 - 8:00

#### **Continental Breakfast**

7:30 - 1:00

### **Exhibit Hall Open**

### ■ Plenary Sessions

8:00 - 9:15

## **Emerging Genetic Technologies: Impact on the Future**

Panelists will highlight the latest trends in genetic technologies and their implications across the life span.

**John Lumpkin**, MD, MPH, Director, Illinois Department of Health

**Elliott Hillback Jr.**, Senior Vice President, Corporate Affairs, Genzyme Pharmaceuticals

Michael S. Watson, PhD, Professor of Pediatrics, Washington University in St. Louis

9:15 - 10:30

### A Diverse Community Perspective on Genetics Research and Testing Community Reactor Panel

Panelists will share their perspectives on issues of genetics research and testing as they relate to their particular communities.

**Judy Gobert**, Dean, College of Math and Sciences, Salish Kootenai College

11:00 - 12:00

### **Enlisting the Community as a Resource**

Panelists will describe their efforts to engage communities in discussions about genetics issues.

**Larry Hudkins**, Past President, National Association of Local Boards of Health

**Toby Citrin**, JD, *Director, Office of Community-Based Public Health, School of Public Health, University of Michigan* 

Morris Foster, Associate Professor, Department of Anthropology, University of Oklahoma

12:30 - 2:00

#### Luncheon -

### National Policy and Program Development: Appropriations and Laws on the Horizon

2:15 - 3:45

#### ■ Concurrent Sessions

Papers will be presented from competitive abstracts.

4:00 - 5:30 Continued presentation of selected papers.

## **Special Sessions and Meetings**

6:00 - 9:00

On-line resources such as HuGE Net, OMIM, Helix, GenLine, and InfoGen will be demonstrated.

### **HuGE Net Meeting**

## Wednesday, December 8

7:30 - 8:30

### **Continental Breakfast**

7:30 - 1:00

### **Exhibit Hall Open**

### **■ Plenary Sessions**

8:30 - 9:30

## Preventing Disease through Genetic Knowledge

Using colon cancer as an example, panelists will present the development of knowledge from basic research through public health research, clinical utility, and, finally, to clinical integration into clinical and preventive medicine.

Paul Wiesner, MD, Director, DeKalb County Board of Health

**Ken Kinzler**, PhD, Associate Professor of Oncology, Johns Hopkins Oncology Center

**Wylie Burke**, MD, PhD, *Director, Women's Health Care Center, University of Washington* 

Ellen Gritz, PhD, Professor and Chair, Department of Behavioral Science, MD Anderson Cancer Center

9:30 - 10:15

### **Privacy and Confidentiality**

The myriad of privacy and confidentiality issues presented by genetics related to medical record privacy will be discussed, as will activities currently underway to assess effective policy options.

James Hodge, Jr., LLM, Principal Investigator, Genetics Legislation: Syntax, Science, & Policy - Analyzing State Legislation, Georgetown University Law Center

10:30 - 11:30

#### Financing of Public Health Functions

Panelists will present strategies to finance the essential public health functions of assessment, assurance, and policy development, particularly as genetics advances place increased pressure on public health's infrastructure.

11:30 - 12:30

## **Closing Plenary**

## Challenge for the Future: Partnerships to Promote Health

The leadership of two public health agencies, CDC and HRSA, will discuss the importance of collaboration to optimally improve health. The session will emphasize not only the importance of collaboration between public health agencies, but also the necessity of public-private partnerships.

**Jeffrey Koplan**, MD, MPH, Director, Centers for Disease Control and Prevention

**Claude Earl Fox**, MD, MPH, Administrator, Health Resources and Services Administration

## CALL FOR ABSTRACTS DEADLINE EXTENDED TO AUGUST 30, 1999!

### **How to Submit a Presentation Proposal**

Conference participants are invited to submit an abstract for platform presentation or for a poster. Abstracts can be submitted either by E-mail or by regular mail. No faxes, please.

- · Complete the call for presentation form.
- Attach a 250 word, or less, abstract of your research or project presentation.
- Formatting instructions: One page, single spaced, font size no smaller than 10 point.
- Mail or email (no faxes) 8 copies of your proposal. Faxed copies will not be accepted.
- Submissions must be received by August 30, 1999.
- Descriptions of each accepted presentation will be reproduced in the conference materials exactly as submitted.

#### **Selection Process**

The Abstract Subcommittee will complete an in-depth review of all proposals that follow the proposal preparation guidelines. Notification: The Program Committee will notify individuals submitting presentations of the results of the review in September 1999.

Complete this form and send it with your abstract. Complete one form for each presentation.

Name				
Degree				
Affiliation				
Mailing Address				
Phone				
FAX				
E-mail				
Abstract Title				
Authors				
Please check one of the following:  Category				
☐ 1. Translation: the continuity of research from genetic discovery to public health utility.				
<ul> <li>2. Legislative and policy issues related to genetics and public health.</li> </ul>				
<ul> <li>3. Education of professionals and the public about genetic knowledge.</li> </ul>				
4. Laboratory issues: technologies, assurance functions, etc.				
☐ 5. Genetics and disease prevention capacity: assessment and expansion.				
$\Box$ 6. Public health performance measurement: informatics, data needs, registries, etc.				
☐ 7. Other: for submissions which do not fit the 6 categories listed.				
Preferred type of presentation:				
☐ Platform ☐ Poster ☐ No preference				
<b>Abstract deadline is August 30, 1999.</b> Please prepare the abstract according to the sample found at http://www.cdc.gov/genetics/temporary/call4abstracts.htm and send to the address or E-mail address below.				

### Where to contact us:

Genetics@cdc.gov

OR write:

Abstract Subcommittee - 2nd Annual Conference, CDC, Office of Genetics and Disease Prevention, 4770 Buford Highway, Mailstop K-28, Atlanta, GA 30341

### **REGISTRATION INSTRUCTIONS**

Please fill out the attached registration form completely (type or print clearly.)

**Payment:** Registration will not be considered complete until payment is received in full. The Second National Conference on Genetics and Disease Prevention will accept checks made payable to ASTHO (Federal ID #35-1044487), and signed Government Purchase Orders or Training Orders.

Mail to: (checks and purchase orders)

Genetics Conference Registration Coordinator 6220 Montrose Road Rockville, MD 20852

Fax to: (purchase orders and training orders only)

Genetics Conference Registration Coordinator (301) 984-9441

Please do not mail your form after you have registered by fax. To receive the Early Bird registration rate, the Registration Coordinator must receive your form and complete payment no later than **October 8, 1999**.

For the Advance discount rate, registration and payment must be received no later than **November 19, 1999**.

**Registration Confirmation:** Confirmation of your registration will be mailed within 3 weeks of receipt of your registration. If you have not received confirmation within this time frame, or if there is an error, please contact Jennifer Leo, Registration Coordinator, at (301) 530-1619, extension 16, or by email at jenniferleo@conferencemanagers.com.

Registration Materials: Name badges, tickets, programs, etc. will not be mailed in advance. Attendees who have registered in advance may pick up their registration materials on-site at the Advance Registration area in the Atrium of the Hyatt Regency Baltimore.

**Cancellation Policy:** 50% of the full registration amount will be refunded if cancellation is received in writing by the Registration Coordinator no later than October 15, 1999. Refunds will not be available for cancellations received after October 15, 1999.

Special Needs: If you require vegetarian meals, special assistance or handicapped accessibility in order to fully participate in the meeting, please check the "Special Needs" box on the registration form, and the Second National Conference on Genetics and Disease Prevention Convention Manager will get in touch with you to discuss your specific needs.

## **Second National Conference on Genetics and Disease Prevention**

# December 6 - 8, 1999 • Hyatt Regency Baltimore • Baltimore, Maryland ADVANCE REGISTRATION FORM

Registration Fees		☐ Please contact me to discuss my special needs. I prefer to be	
Early Bird	\$150	contacted by phone/fax/e-mail (circle one).	
(registration and payment mus	t be received by October 8, 1999)	Your conference registration fee includes the following social	
Advance	\$200	events:	
(registration and payment must be received by November 19, 1999)		Maryland Science Center (Monday, December 6, 7:00 pm -10:00 pm )	
After November 19, 1999 \$250 and On-Site		Monday Lunch (Monday, December 6, 12:30 pm - 2:00 pm) Tuesday Lunch (Tuesday, December 7, 12:30 pm - 2:00 pm)	
and On-Site		You may purchase additional tickets for your spouse or other	
Important Dates		guest (see below).	
October 8, 1999	Early Bird deadline	<i>g</i> ().	
October 15, 1999	Last day to receive 50%	Registration fee (please check one) \$	
N 1 10 1000	cancellation refund	☐ Early Bird (before October 8, 1999) \$150	
November 19, 1999 December 6, 1999	Advance Discount deadline	Advance (before November 19, 1999) \$200	
December 0, 1999	Conference begins!	☐ After November 19, 1999 and on-site \$250	
Please type or print	all requested information:	Additional Maryland Science Center Tickets (\$40 per person)	
□ D. □ D. □ D. M	□ M-	# Total \$	
□ Dr □ Mr □ Mrs	☐ Ms		
		<ul> <li>Additional Monday Lunch Tickets (\$25 per person)</li> </ul>	
First Name		# Total \$	
		"	
Last Name		_	
		Additional Tuesday Lunch Tickets (\$25 per person)	
Degree (MD, PhD, MPH, 6	etc)	— # Total \$	
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NI' 1 /I	1 11		
Nickhame/now your name	should appear on your badge	<b>Total Due</b> \$	
		PAYMENT	
Title		Registrations without complete payment will be returned. Please	
		make checks and Purchase Orders/Training Orders payable to	
Organization		ASTHO (Federal ID# 35-1044487).	
		Amount Enclosed \$	
Address			
		☐ Check enclosed☐ Signed Government Purchase Order or Training Order☐ Check enclosed☐ Check e	
G'.		- enclosed	
City			
		By what type of agency are you employed?	
State		<ul><li>─ ☐ Health Department</li><li>☐ Federal Agency</li></ul>	
		☐ Academia	
Zip		─ □ Public Interest	
Zip		☐ Industry	
		□ Other	
Country		Is receiving continuing education credits important to you?	
		☐ Yes	
Phone (include area code)		— □ No	
		If offered, for which continuing education credits would you	
Fax (include area code)		apply?	
,		□ CME	
E 1 11		□ CEU □ Other	
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Monday, December 6	Tuesday, December 7	Wednesday, December 8
7:30 am - 5:00 pm	7:30 am - 8:00 am	7:30 am - 8:30 am
Registration	Continental Breakfast	Continental Breakfast
8:30 am - 10:00 am	7:30 am - 1:00 pm	7:30 am - 10:00 am
Welcome Remarks and Keynote Address	Exhibit Hall Open	Registration
	7:30 am - 5:00 pm	7:30 am - 1:00 pm
10:00 am - 10:30 am <b>Break</b>	Registration	Exhibit Hall Open
	8:00 am - 10:30 am	8:30 am - 10:15 am
10:30 am - 12:00 pm Plenary Session	Plenary Sessions	Plenary Sessions
12:00 pm - 12:30 pm	10:30 am - 11:00 am Break	10:15 am - 10:30 am <b>Break</b>
Break	Break	
12.20 2.00	11:00 am - 12:00 pm	10:30 am - 11:30 am
12:30 pm - 2:00 pm Luncheon Speaker	Plenary Session	Plenary Session
Eulencon Speaker	12:00 pm - 12:30 pm	11:30 am - 12:30 pm
2:00 pm - 2:30 pm	Break	Closing Plenary
Break	12.20	
2:30 pm - 4:00 pm	12:30 pm - 2:00 pm Luncheon Speaker	
Plenary Session	Euncheon Speaker	
•	2:00 pm - 2:15 pm	
4:00 pm - 4:15 pm <b>Break</b>	Break	
	2:15 pm - 3:45 pm	
4:15 pm - 5:45 pm Concurrent Sessions	Concurrent Sessions	
	3:45 pm - 4:00 pm	
5:45 pm - 7:00 pm <b>Break</b>	Break	
	4:00 pm - 5:30 pm	
7:00 pm - 10:00 pm Maryland Science Center Social Event	Concurrent Sessions	
Mai yianu Science Center Social Event	5:30 pm - 6:00 pm	
	Break	
	6:00 pm - 9:00 pm	
	Demonstrations of Online Resources HuGE Net Meeting	